CROHN'S & COLITIS UK



NEWSLETTER

SPRING 2023

East Cornwall & West Devon Network

GWENNIE'S STORY

Gwennie Froment is "70 years young", has Ulcerative Colitis and Leukaemia, and teaches Zumba. What an amazing lady! Here, in her own words, is her story ...

"I have had bowel issues for as long as I can remember; piles, constipation, mucus, and I was told I had 'sluggish' bowels! Around 2020 I started having different symptoms, more mucus that I couldn't hold in, and bleeding. We moved house around this time and I was also waiting to start training as a Zumba instructor. Because of these events I put off speaking to my GP. I had a negative bowel cancer test result and wasn't unduly worried.

In July 2021 I took my Instructor training and couldn't wait to start running classes. I was losing weight quite rapidly and my symptoms had worsened so I saw my GP who suggested doing some routine bloods. The morning after the blood tests I had a phone call from a doctor at Derriford Hospital asking me to come in straight away. I was so scared!

I went to a haematology ward where I was informed I had a type of Leukaemia called Chronic Myeloid Leukaemia. The haematologist told me it could be controlled by a tablet every day. I asked him if my bowel issue could be linked but he didn't think so.

After the shock of that diagnosis I was monitored monthly. My haematologist asked how I was and I

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said my biggest problem was my bowels. I was scared to go anywhere. I had urgency and lots of blood and mucus. I was still teaching Zumba but having to dash to the loo during classes! The haematologist referred me for 'top and tail' scopes and that's when the proctitis was found!

We have been struggling with treatment because some drugs have been incompatible with the Leukaemia treatment. My Leukaemia is responding to treatment and just recently I have been started on Infliximab which seems to be working!

(Continued overleaf)

GWENNIE'S STORY (CONTINUED)



I have to say *a huge thank you to the wonderful IBD nurses at Derriford* who are always there for help and advice.

My Zumba has been my lifeline. It lifts my spirit, helps keep me fit and happy, and my ladies are so encouraging. I have a collection pot for Crohn's & Colitis UK which they drop change into. I also sell Zumba products and put all proceeds into the pot. One of my ladies makes cards and sells them. She kindly donated money from her sales. I think I have sent the charity about £100 so far.

I am 70 years young, I have 2 long term conditions and I teach 3 Zumba classes a week. I will keep going as long as I can!"



Gwennie responded to our request for people to tell us their stories and I'm sure you'll agree, hers is a truly inspiring one! She didn't ask for publicity for her business but we're very happy to share this information:

Gwennie's classes are held near Launceston in the villages of Lawhitton and Milton Abbot. The classes are low impact so suitable for all abilities and both venues have loos. If you're interested in finding out more, please contact Gwennie direct on dith1952@gmail.com or via her Facebook page - Gwennie's Zumba & Gold, https://www.facebook.com/groups/555889862903409/

If you have a story to tell about raising funds or awareness locally then please get in touch at ecwd@networks.crohnsandcolitis.org.uk or message us on our Facebook page

PLYMPTON MAY FAIR

We hope to see lots of you at this year's *May Fair at Harewood House in Plympton*. Last year was the first time we'd had a stall there and we enjoyed it so much we were very happy to be invited back!

We'll be selling cute hand-knitted characters and beautiful handmade jewellery, with all proceeds going to the charity. There will be lots of other stalls and activities both inside and outside with plenty for all the family to enjoy, so do come along.



FEB FB LIVESTREAM

After a gap of a year it was great to restart our *Facebook livestreams* in February. Lots of you posted topics/questions during the half hour session and *Senior IBD Nurse Kathy Webb* answered all your queries, ably assisted by volunteers Jane and Lindsay.

We chatted about the differences between IBS and IBD, new medications, vitamins for



children, when to have surgery, side effects and differences between the many biologics, and fecal transplants, among other topics.

If you missed it you can still find the livestream, with subtitles, on our YouTube channel at https://www.youtube.com/watch?v=dNf84H4aOBU. There's a list of topics along with the time within the video that they appear so you can jump straight to the bit you're interested in.



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This lovely man, Phil Hearnden, is planning an epic journey around the coast of the UK on

his motorbike, raising funds and awareness for Crohn's & Colitis UK! He'll be setting off on World IBD Day and should be in Plymouth around 2nd/3rd June so we're hoping to catch up with him on his way through. Here's what he has to say about his unique journey ...

"My name is Phil I would like to invite you all on my journey around the coast of the UK as I ride my motorbike over 3,500 miles raising money for Crohn's & Colitis UK.

I have been fighting Crohn's disease since the age of around 11 and *diagnosed at 13 years old*. Currently, stats show that there are half a million suffers of Crohn's and Colitis in the UK. These numbers are staggering.

The starting point of my journey will take place at Haverfordwest Hospital in West Wales which is where my life changed in 2014 after an emergency operation. I ask you to follow

my journey around the coast of the UK taking in all of the sights and scenery this island has to offer. Amongst the big land marks, I will visit the place with the UK's longest train station name in North Wales. John O' Groats, the most easterly point, Ness Point, and Lands End, to mention a few.

I will be sharing all of this on *Instagram* #*Trucker-To-Biker* for all updates and route plans.



I am looking forward to doing this journey for this amazing cause. Please follow me as I embark on this amazing adventure for all those Crohn's and Colitis warriors."

If you'd like to support Phil on his impressive trip, you can sponsor him on his JustGiving page at https://www.justgiving.com/page/phil-hearnden-1678904138705. And don't forget to keep checking our Facebook page to see where he's got to and to find out where and when we'll be meeting him.

Coming soon!

QUIZ

FRIDAY 26th MAY

THE STADDY



144 Staddiscombe Rd, Staddiscombe, PL9 9LT

KATHY STAYS HOME (2 DAYS A WEEK)



There can't be many people in the Plymouth area with Crohn's Disease or Ulcerative Colitis who haven't come across Kathy Webb, Senior IBD Nurse at Derriford Hospital. She's been in fulltime nursing for 37 years and a specialist nurse here since 2002, leading a team of dedicated IBD nurses who are always there to answer our queries and give support and advice.

Hearing that Kathy was reducing her hours to 3 days a week left many of us with mixed emotions. On one hand, we were devastated to think that she wouldn't be there every day with her practical, down-to-earth advice and warm, friendly manner. But on the other hand we all know how hard she works - as one Facebook comment put it "Part time hours for Kathy is still probably 40 hours though"!

Kathy is unanimously popular with colleagues and patients alike and in summer 2018 she was deservedly awarded the *Dr Kate Granger Care and Compassion Award*. She's also been a fantastic support to our local volunteer team and regularly *appears on our livestreams to answer your medical queries*.

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We hope Kathy thoroughly enjoys her extra time off work, relaxing with her wonderful husband, John, and going for long walks with her gorgeous 'fur baby', Cara.

The comments on this page, all taken from Facebook after we posted about Kathy's reduced hour working, prove how much love there is for her.

"Incredible nurse and helped me through some really tough times"

"Kathy was so caring and compassionate as well as being an expert in her field!"

"I couldn't have got though all these years without her"





"She's absolutely amazing and I feel so lucky to have had her support all this time!"

"Always smiling and so approachable"

"There are so many things I could say about you, all good obviously, but I'd be here for ages"

"It takes a special kind of nurse to understand, empathise and support patients suffering with IBD"

"Such an amazing, caring and compassionate lady"

"An incredible, amazing nurse"

"Kathy was so patient with me through it all when I was young and scared"



"Kathy is fabulous, so dedicated, so caring"

DERRIFORD IBD NURSE CONTACTS
PHONE: 01752 439224
EMAIL: plh-tr.ibd-advice@nhs.net

COFFEE MORNING SUCCESS



It was brilliant to see so many people at our second *coffee morning* of the year! Once again, the manageress at *Costa at Plymouth Gateway* (near Wrens) saved the section just inside the door but there were so many of us we were pretty crammed in as you can see in the photo! There were even a couple of people sitting across the other side of the gangway!

As usual we caught up with old friends and also shared experiences and advice with those who've been more recently diagnosed.

These coffee mornings are proving to be very popular so we'll definitely be continuing with them. Our next one is in June at the same place (see below) but we hope to hold one in Cornwall too, maybe in July. Hope to see you there!

Sat 3rd June 10.30 to noon

Costa Coffee 270 Plymouth Rd PL6 8ET

(near Wren and Sofology)



If you're raising money locally for Crohn's & Colitis UK please get in touch with us so we can promote and support your event at

ecwd@networks.crohnsandcolitis.org.uk

or message us on our **Facebook page**

CONTACT US

CROHN'S & COLITIS UK

EAST CORNWALL & WEST DEVON NETWORK

Leads: Shas Chilcott and Dani Brown

2 0300 222 5700 (via Helpline Service)

Website: www.crohnsandcolitis.org.uk/ecwd



crohnscolitisuk.ecwd



@CrohnsColitisECWD

CONTACT FOR LOCAL IBD NURSES

Derriford Hospital, Plymouth

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Mon-Fri & 9am-5pm (except English bank holidays). Answer phone service outside these hours.

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WINTER WORKOUT RAISES £400,000

What a fantastic start to 2023! Over 4,100 people from across the Crohn's and Colitis community joined in the Big Winter Workout, including our very own volunteer team member, Gemma.

The challenge was to do at least 31 minutes of physical activity every day throughout the 31 days of January. People chose a huge variety of activities, from walking and swimming to hula-hooping and surfing! Together they raised over £400,000! Truly amazing!

If you have received this newsletter by post and would be happy to receive future editions by email please send your name, membership number and email address to

networks@crohnsandcolitis.org.uk

This will save the Network valuable funds which can be used to benefit all those affected by Crohn's or Colitis.

The East Cornwall & West Devon Network has made every reasonable effort to ensure the content of this newsletter is accurate but accepts no responsibility for any errors or omission.

The views of the contributors do not necessarily reflect the views or policies of Crohn's & Colitis UK and no reference in this newsletter to any product or service is intended as a recommendation.

Dates for your Diary

Mon 24th April: FB livestream

Sat 13th May: May Fair

Fri 26th May: Quiz

Sat 3rd June: Coffee Morning

Make a note!